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ABSTRACT

There are over 20,000 Assistive technologies (ATs) available today, thereby giving persons with disabilities unprecedented opportunities for full societal participation, yet women with disabilities are frequently less able to take full advantage of these opportunities. In addition to lack of information about ATs and the inability in many cases to afford them, as a group women have typically not had much exposure to and experience with technologies and can find them intimidating and frustrating. This paper first presents a definition of assistive technologies, giving examples of different types. It then examines who uses ATs and identifies the desirability of a model to more appropriately match women and technology. Characteristics of the technology and service delivery, of the disabled person, and of the psychosocial environment in which he or she exists are discussed. The final section of the paper focuses on achieving the best and most appropriate match of person and AT. A list of sample questions to consider about a device's usability is included at the end. (Contains 16 references.) (AEF)

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The Different Perspectives Women with Disabilities Bring to Technology Use

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Abstract

Assistive technologies make possible negative as well as positive changes for women with disabilities. Technology alone is rarely the answer to a person's enhanced quality of life. Assistive technologies can help a woman access more opportunities and exercise more options, but they require support services and training, attention to the person's basic needs, personality, preferences, and capabilities and the characteristics of the psychosocial environment in which the device will be used.

The Different Perspectives Women with Disabilities Bring to Technology Use

The National Council on Disability (2000) surveyed 2,000-plus users of assistive technologies (AT) throughout the U.S. with consistent results across all demographic and geographic groups and disability types: The two biggest barriers to accessing AT identified were (a) lack of information and knowledge about appropriate AT, and (b) lack of funding to purchase the needed AT. According to the report:

> Consistently, those who responded to the survey do not have information on what AT is available, where to get it, who pays for it, where to get an evaluation, or what their rights are. Overwhelmingly, respondents said they do not have the money to purchase AT--either they did not have the out-of-pocket cash, their insurance companies did not cover it at all or denied their claims, or no public funding available was available. Other common themes were the lack of trained, qualified professionals to evaluate what AT was appropriate; the difficulty finding and trying out AT; the red tape and bureaucracy of public programs and insurance companies; the difficulty of keeping pace with technology developments; the lack of maintenance and support; and the lack of access to AT in other areas, such as housing and transportation [http://www.ncd.gov/newsroom/publications/assisttechnology.html].

According to the National Institute on Disability and Rehabilitation Research (NIDRR), approximately two-thirds of those who did get an AT paid for

it out of pocket (Seelman, 1998). In far too many cases, however, the respondents said that these barriers led them to go without an AT or an upgraded AT. Having to go without an AT has a direct impact on quality of life, societal participation and involvement, and the onset of primary and secondary health conditions.

Furthermore, as we have known for decades, women are often poorer than their male counterparts and can face multiple barriers to finding and paying for the most appropriate ATs for their use (e.g. National Council on Disability, 1996; Asch & Fine, 1988; Deegan and Brooks, 1985; Willmuth & Holcomb, 1993). Ironically, there are over 20,000 ATs available in the marketplace today, thereby giving persons with disabilities unprecedented opportunities for full societal participation, yet women with disabilities are frequently less able to take full advantage of these opportunities. In addition to lack of information about AT and the inability in many cases to afford AT, as a group women have typically not had much exposure to and experience with technologies and can find them intimidating and frustrating. Certainly, many women do use AT devices regularly and with great satisfaction, but many others use them infrequently and with reluctance, avoid them entirely, or try them only to abandon their use.

Definition of Assistive Technologies

Assistive technologies or devices are mechanical, electrical, or computerized tools for enhancing the routine functioning of people who have physical limitations (disabilities). An assistive technology device, as first defined in the "Technology-Related Assistance of Individuals with Disabilities Act of 1988" (P.L. 100-407), is "any item, piece of equipment, or product system, whether acquired commercially off the shelf, modified or

customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities." This definition of assistive devices has been used in each piece of legislation related to persons with disabilities passed since 1988 and it is the standard definition used in the field.

Assistive devices are really just what the term implies; they assist individuals in performing certain functions like getting around in wheelchairs and in specially designed vans. Without assistive devices made possible by relatively low-cost electronic components and computers, many people with physical disabilities would be leading isolated and dependent lives.

Assistive devices range from low-tech aids such as built-up handles on eating utensils to high-tech, computerized communication systems and battery-powered wheelchairs. When people speak of "high-tech assistive devices" or "complex assistive technologies," they are usually referring to ones with electronic components. Computers per se are not considered assistive technologies. Rather, they are an access technology which means many devices operate and work through the control of a computer.

There are several ways to categorize assistive technologies: One is according to the functional purpose for which the device or assistive technology is prescribed. Three examples are:

1. Mobility devices: powered wheelchair systems, vehicle control systems, and sonic guides.
2. Augmentative and alternative communication (AAC) systems: technologies that enable a person with limited speech or no useable speech to visually display their communication or speak through synthesized speech output.

3. Sensory devices: reading devices for people with visual impairments; personal FM systems for persons with hearing loss.

Who Uses Assistive Technologies

We know that the highest rate of assistive technology use occurs (a) the more limited an individual's functioning and (b) when viable alternatives to use do not exist or are not available (Scherer, 2000; Galvin & Scherer, 1996). For example, a woman born with cerebral palsy who cannot walk unassisted for more than 10 feet will use a wheelchair more than one who has difficulty with only balance.

The assumption that all people with disabilities have the desire to effectively utilize a complex or computer operated device is not an accurate one. Until recently, women in our society have traditionally received little exposure to technical perspectives and tended to be uninformed about computers. While women today use computers and other technologies as effectively as males, many remain disinterested in the complex and sophisticated products and also in pursuing high-tech careers (American Association of University Women, 2000; Littrell, 1991). To illustrate, Dr. Caren Sax, San Diego State University, teaches an on-line assistive technology course to practicing rehabilitation counselors throughout the U.S. Over the five years she has been teaching this course, she has noticed some patterns:

> ... women, as the recipients of AT, are concerned with simplicity and low maintenance. Aesthetics are in there, but as a very broad generalization ... they want something simple to use and that won't break down. The males don't seem to mind it being a little more high tech, but are focused on

having the AT do what they want...so more focused on function in general (Caren Sax, personal communication , July 7, 2000).

The preferences of adolescents will be different from adults. Worldwide, adolescents with disabilities tend to be are more concerned with their appearance and projected image than older adults. Many older adult women with disabilities have traditionally grown up in dependent roles, with few technology-using role models, and encouraged to be docile and uncomplaining. While research shows that this is true for aging women in general (e.g. American Association of University Women, 1992), it is especially the case for women with disabilities. Many were taught to be passive about their preferences. Too often, women with disabilities are still excluded from decisions regarding assistive technologies and other matters which affect their lives. This perpetuates the belief that women with disabilities are passive and incompetent.

Recent reports from the U.S. National Council on Disability (1997) and the European Commission's Telematics Applications Program (Bellabio & Moran, 1998) acknowledge that older individuals and women with disabilities often are poorly matched with a product they need to use regularly. As they age, consumers have a clear preference for products that they do not have to think about (are easy to care for and maintain and which accommodate to them, not vice versa). When presented with a choice, consumers will select assistive devices, as they do with any product, according to characteristics that satisfy their preferences.

The Desirability of a Model to More Appropriately Match Women & Technology

Previous research (e.g. Scherer, 2000) has focused on technology use as being an outcome of the interaction of: a) the particular technology (design, service delivery), b) the potential user's unique "disability experience," abilities and personality (judgment, expectations), and c) and the psychosocial environment (social support, training and education) in which the person will use AT. Ultimately, the goal is to find methods for matching a particular device with an individual in a way that will increase the likelihood of successful use and enhance the user's quality of life.

Characteristics of the Technology and Service Delivery

A woman with one or two hearing aids, or with a communication system, is "ego involved" to an extent different from one with an "impersonal" environmental control system and levels of comfort with use, even around family members, vary widely. Feelings of being conspicuous are compounded when assistive technologies are designed to look functional and utilitarian for funding sources and, as a result, leave many women feeling deviant and stigmatized.

Assistive technologies are not used if other support services are not there. For example, a specially-equipped van is less useful when there are no handicapped parking spaces. Homebound persons (such as some elderly people) and those in remote and rural areas, may be unfamiliar with many devices because they may not have access to peers or trained professionals to help them learn to use them properly.

Characteristics of the Person

A person's psychological acceptance of their disability and readiness to depend on sophisticated technologies varies according to the person's prior technology use and predispositions to use, history of coping and adaptation and degree of available psychosocial and material support. Examples from the book, *Living in the State of Stuck: How Technology Impacts the Lives of People with Disabilities* (Scherer, 2000) show how too often these factors are not taken into account and the result is users' frustration with technologies provided to them and technology non-use.

Technical comfort. For women who appear to be uncomfortable with or intimidated by technologies, the potential of achieving limited gains through the use of an assistive device may not be worth the anxiety or discomfort involved in its use. While this situation will no doubt change as women become increasingly exposed to technologies at very young ages, women today without the education, socialization or exposure to the use of a computer can have a distrust of it and exhibit anxiety when faced with one. Being anxious makes it more difficult to learn the skills to operate it. When feeling anxious about the use of a technology in public, interactions with others can become more strained, especially since assistive devices serve as signs of disability and set a person apart as being different. They can both physically and socially separate women with disabilities from those without disabilities. Since a person's self-esteem and self-image are built up over time through interactions with other persons, assistive devices which serve as stigmatizing symbols have the ability to negatively define those interactions and ultimately a person's self-image.

Cognitive abilities and aptitude. People differ in their aptitudes to effectively use

assistive devices. The more sophisticated any device is, the more complicated the training may be in how to use that device. The emphasis technology places on cognitive and intellectual capabilities, as opposed to motor and physical skills, has opened many opportunities for persons with physical disabilities but has created some barriers for women who were not allowed to pursue courses in math and science. Yet, learning styles typifying women can place them at an advantage: Women tend to have a divergent approach to problem-solving (seeing many solutions or possibilities) as opposed to a convergent approach which attempts to focus on the one best solution. When learning new information, they may also modify or expand their existing knowledge base and accommodate new ideas more easily than men who have been trained to try and fit new information into an existing schema (assimilation). Thus, while women may have some disadvantages as far as their socialization, education, and exposure to technologies, their learning styles can help them to catch-up.

Judgment and preference. Many persons prefer to use a personal care attendant or what they themselves have, however limited, as opposed to a mechanical replacement for their limited functions. They want the "human touch" and actively strive to "not look different."

Adjustment and Outlook. Factors affecting a person's outlook include depression and pessimism arising from the process of adjustment to a disability. People with disabilities attach different meanings to what has happened to them and what their future is likely to be like. Pre-existing temperament and ways of coping are just two factors that can influence the length and quality of the recovery and rehabilitation process and adjustment.

Attending to and monitoring the self-esteem of the client is important in the timing of assistive technology recommendations. Assistive technology use requires an admission to the self that one cannot, and possibly never will, do a functional task on one's own. It requires admitting a loss, weakness, or deficit and this can be distressing. A push for premature device use can be a mistake for those individuals who, as one person has said, "first need time to get used to just the thought of it."

Characteristics of the Psychosocial Environment

When we think about people with disabilities living and working in different environments, we are accustomed to thinking primarily in terms of the physical accessibility of those environments. But environments have other characteristics that are equally deserving of attention. For example, different environments tend to draw people of varying ages, cultural backgrounds, educational and leisure interests, and so on. The attitudes of the individuals in an environment towards the inclusion of persons with disabilities is good information to have in order to make inclusion as smooth as possible.

Exposure and opportunity. Factors such as environmental accommodations, available resources (e.g. private insurance for specialized treatment) and special opportunities (e.g. placement in a rehabilitation center with the newest equipment) are key influences on AT awareness and use.

The individual's cultural identity and the values and norms of that culture should be considered. For example, we know that in some countries, such as India, many adult women spend the majority of their time in the home and near floor-level. These users are more interested in a wheelchair with a low seat than one that can handle a variety of road

surfaces (Mulholland, Packer, Laschinger, Lysack, Wyss & Balaram, 2000). In such countries as Denmark, on the other hand, where people with disabilities are often out in the community, durable wheelchairs which can handle a variety of outdoor conditions is far more important.

One of the most common reasons for the non-use or reluctant use of an assistive technology is that it was forced upon the person by family members or therapists. Just as some families will resist the use of technological assistance, as many will purchase anything they believe will help only to discover that the individual either does not want to use it or cannot use it. Women, regardless of age, seem especially prone to such external direction.

Consumers of assistive technology services include persons with disabilities (primary consumers) and their family members and caretakers (secondary consumers). It is important to involve at the outset all who will be affected by the assistive technology, keeping in mind the function to which the technology will be put and the environment in which it will operate and be used.

Achieving the Best and Most Appropriate Match of Person and AT

When recommending a device for a person's use, it is crucial to assess strengths as well as limitations, evaluate the existence of ancillary limitations (such as low vision for the user of a device with a graphic display), select the most cost efficient device that is the best ergonomic and aesthetic match, provide training in use and maintenance, and follow-up to determine the extent to which the device is meeting the consumer's needs and determine any secondary effects it may have presented. By keeping in mind a) the

characteristics of the psychosocial environment in which the device will be used, b) the person's personality and preferences, c) and the capabilities and characteristics of the technology under consideration, the recommendation will, thus, emerge from that person's unique needs and will be consumer-driven.

The sum total of the characteristics discussed up until now come to define the perspective of the user regarding an assistive technology's *usability*. Device *usability* is what makes a consumer prefer, select, and use one product over similar others. The particular device judged to have the most *usability* will be the one selected for initial use. Then, over time, the continued use of that device will be determined by its on-going performance and usefulness for the user in actual situations of use. If it continues to meet the individual's performance expectations and is easy and comfortable to use, then a good match of person and technology has been achieved. This can only be achieved through a cycle of device and feature evaluation, selection, accommodation, and use in various environments. To assist consumers in determining and comparing the *usability* of devices, a group of peer mentors working through the Rochester Center for Independent Living (Rochester, NY) prepared a workbook containing guiding questions to consider. Sample questions are included in Table 1.

As the diversity of both products and the users of those products expand, it is increasingly important to be able to understand the different needs and preferences among users and to provide each consumer with the products he or she needs and wants. That preferences vary is not only crucial for psychologists and providers to understand when matching a person and a device, but also for manufacturers and vendor to consider as they design and market their products. In the case of such products as wheelchairs, users may

not have choice over whether or not to use it, but can exercise choice in their selection of style and the environments in which they use it. This *user involvement and empowerment* is a key focus of research and practice efforts in the U.S. and throughout the European Commission (e.g. Galvin & Scherer, 1996; EUSTAT Consortium, 1997, 1998). Not only does attention to a user's personal preferences help assure a good user-product fit, but it can foster a sense of control and empowerment in the user over product utilization. To help users feel in control and secure that a product is the right one for them, psychologists, caregivers and providers need to take the time to follow-up and check users' feelings of comfort and security with their assistive technologies.

All assistive technologies, but especially the "non-essential" ones, might achieve higher utilization rates by women if more female users were available as role models. Peer modeling and support is not only important in presenting assistive technologies as options to individuals, but in learning adaptive behaviors in general and for the development of self-confidence and a positive identity.

One consideration of such great importance that it requires special emphasis is the active involvement of the female user in the decision-making process. Too often, women with disabilities are excluded from decisions regarding assistive technologies. This perpetuates the belief that women with disabilities are passive and incompetent. While assistive technology providers are usually very responsive to the physical needs of women with disabilities, there is frequently less attention given to the psychological and social aspects of assistive device use. Thus, psychological services need to be emphasized in a comprehensive rehabilitation program in order to enable the consumer to discuss and work through feelings, attitudes, and fears that interfere with rehabilitation. Psychologists,

trained to have an interactive, comprehensive and interdisciplinary approach to problem intervention, can "look at the whole picture." They can help people resolve identity confusion and come to terms with and enhance their own unique circumstances. They can also educate and provide support to other members of the family.

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TABLE 1: SAMPLE QUESTIONS TO CONSIDER ABOUT A DEVICE'S *USABILITY*

For persons acquiring a device for the first time, and for those who need to replace an old or worn-out one, a great deal of effort and time is required to find the most appropriate one. Your responses to the items below assist both you (as consumer and technology user) and the service provider in making choices best suited to your needs. In many cases, correct choices help avoid the frustration caused by technology that is not compatible with your preferences, personality, and environments. Because we know how hard it is to figure out what questions to ask and how easy it is to forget what we do wish to ask, we came up with a list of questions. The questions are divided into sections as examples for you to have handy when you are talking to professionals.

Each question has a box to check. A check mark can indicate those questions with "yes" answers. A line drawn through the box can indicate those questions with "no" answers.

Characteristics and Resources of the Person

Can I use this device as independently as I want?

☐ Do I feel comfortable using this device?

☐ Do I feel in control of this device?

☐ Have I acted on impulse or have I thought this selection through?

Characteristics and Requirements of the Milieu or Environments of Use

☐ Will this device meet my needs in various situations and environments?

☐ Do I need parts because of the weather conditions in my area?

☐ Do I need special parts because of the geography in my area?

☐ Does the device have the stability I need in a variety of situations and environments?

TABLE 1: SAMPLE QUESTIONS TO CONSIDER ABOUT A DEVICE'S *USABILITY*[*], cont.

- ☐ Does the device have the durability I need in a variety of situations and environments?
- ☐ Do I need to make changes in my environments to accommodate my use of this device?
- ☐ Does the assistance I need to use this device exist?

Characteristics of the Technology

- ☐ Can I try the device before making a commitment to it?
- ☐ Is the size and weight of this device manageable?
- ☐ Could this device be adapted if there are changes in my functional abilities, activities, and/or size?
- ☐ Are repairs and parts available quickly?
- ☐ Have I REALLY looked the product over carefully?

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[*] Adapted from Scherer (2000).

Author's Biographical Sketch

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